

## **Data Collection Worksheet**

Please Note: The Data Collection Worksheet (DCW) is a tool to aid integration of a PhenX protocol into a study. The PhenX DCW is not designed to be a data collection instrument. Investigators will need to decide the best way to collect data for the PhenX protocol in their study. Variables captured in the DCW, along with variable names and unique PhenX variable identifiers, are included in the PhenX Data Dictionary (DD) files.

A. STROKE HISTORY
1. Have you ever been told by a physician that you had a stroke?
[] Yes
[ ] No [Go to Item 3]
2. When did the first stroke occur?
/
m m y y
B. SUDDEN LOSS OR CHANGE OF SPEECH
3. Have you ever had any sudden loss or changes in speech lasting 24 hours or longer?
[ ] Yes
[ ] No [Go to Item 7]
[ ] Dont know [Go to Item 7]
4. Did the episode come on suddenly?
[ ] Yes
[ ] No
5. Do any of the following describe your change in speech?
[READ ALL CHOICES]
5a. Slurred speech like you were drunk?

	[ ] Yes
	[ ] No
	[ ] Dont know
5b.	Could talk but the wrong words came out?
	[ ] Yes
	[ ] No
	[ ] Dont know
5c.	Knew what you wanted to say, but the words would not come out?
	[ ] Yes
	[ ] No
	[ ] Dont know
5d.	Could not think of the right words?
	[ ] Yes
	[ ] No
	[ ] Dont know
	[IF MORE THAN ONE OF ITEMS 5a-5d INDICATED, ASK "WHICH OF THESE MOST DSELY DESCRIBES THE PROBLEM?"]
	[ ] Slurred speech
	[ ] Wrong words came out
	[ ] Words would not come out
	[] Could not think of the right words
	While you were having your episode of change in speech, did any of the owing occur? [INCLUDE ALL THAT APPLY]
6a.	Numbness or tingling?
	[ ] Yes
	[ ] No [Go to Item 6c]
6b.	Did you have difficulty on:

[READ ALL CHOICES]
[] The right side only
[] The left side only
[ ] Both sides
6c. Paralysis or weakness?
[ ] Yes
[] No [Go to Item 6e]
6d. Did you have difficulty on:
[READ ALL CHOICES]
[] The right side only
[] The left side only
[ ] Both sides
6e. Lightheadedness, dizziness, or loss of balance?
[] Yes
[ ] No
6f. Blackouts or fainting?
[] Yes
[ ] No
6g. Seizures or convulsions?
[] Yes
[ ] No
6h. Headache?
[] Yes
[ ] No
6i. Visual disturbances?
[ ] Yes

[ ] No [Go to Item 7]
6j. Did you have:
[READ ALL CHOICES UNTIL A POSITIVE RESPONSE IS GIVEN]
[ ] Double vision
[] Vision loss in right eye only
[ ] Vision loss in left eye only
[] Total loss of vision in both eyes
[] Trouble in both eyes seeing to the right
[] Trouble in both eyes seeing to the left
[] Trouble in both eyes seeing to both sides or straight ahead
C. SUDDEN LOSS OF VISION
7. Have you ever had any sudden loss of vision, or blurring, lasting 24 hours or longer?
[ ] Yes
[ ] No [Go to Item 11]
[ ] Dont know [Go to Item 11]
8. Did the episode come on suddenly?
[ ] Yes
[ ] No
9. During the episode, which of the following parts of your vision were affected?
[READ ALL CHOICES]
[] Only the right eye [Go to Item 10a]
[ ] Only the left eye [Go to Item 10a]
[ ] Both eyes
9a. Did you have:
[READ ALL CHOICES UNTIL A POSITIVE RESPONSE IS GIVEN]

	[ ] Trouble seeing to the right, but not to left
	[] Trouble seeing to the left, but not to right
	[] Trouble seeing both sides or straight ahead
	While you were having your loss of vision, did any of the following occur? LUDE ALL THAT APPLY]
10a.	Speech disturbance?
	[ ] Yes
	[ ] No
10b.	Numbness or tingling?
	[ ] Yes
	[ ] No [Go to Item 10d]
10c.	Did you have difficulty on:
[REA	D ALL CHOICES]
	[] The right side only
	[ ] The left side only
	[ ] Both sides
10d.	Paralysis or weakness?
	[ ] Yes
	[ ] No [Go to Item 10f]
10e.	Did you have difficulty on:
[REA	D ALL CHOICES]
	[] The right side only
	[ ] The left side only
	[ ] Both sides
10f.	Lightheadedness, dizziness, or loss of balance?
	[] Yes

[ ] No
10g. Blackouts or fainting?
[ ] Yes
[ ] No
10h. Seizures or convulsions?
[ ] Yes
[ ] No
10i. Headache?
[ ] Yes
[ ] No
10j. Flashing lights?
[ ] Yes
[ ] No
D. DOUBLE VISION
11. Have you ever had a sudden spell of double vision, which lasted 24 hours or longer?
[ ] Yes
[ ] No [Go to Item 14]
[ ] Dont know [Go to Item 14]
11a. If you closed one eye, did the double vision go away?
[ ] Yes
[ ] No [Go to Item 14]
[ ] Dont know
12. Did the episode come on suddenly?
[ ] Yes
[ ] No

13. While you were having your double vision did any of the following occur? [INCLUDE ALL THAT APPLY]
13a. Speech disturbance?
[ ] Yes
[ ] No
13b. Numbness or tingling?
[ ] Yes
[ ] No [Go to Item 13d]
13c. Did you have difficulty on:
[READ ALL CHOICES]
[] The right side only
[] The left side only
[ ] Both sides
13d. Paralysis or weakness?
[] Yes
[ ] No [Go to Item 13f]
13e. Did you have difficulty on:
[READ ALL CHOICES]
[] The right side only
[ ] The left side only
[ ] Both sides
13f. Lightheadedness, dizziness, or loss of balance?
[ ] Yes
[ ] No
13g. Blackouts or fainting?
[ ] Yes

[ ] No
13h. Seizures or convulsions?
[ ] Yes
[ ] No
13i. Headache?
[ ] Yes
[ ] No
E. SUDDEN NUMBNESS OR TINGLING
14. Have you ever had sudden numbness, tingling, or loss of feeling on one side of your body, including your face, arm, or leg which lasted 24 hours or longer?
[ ] Yes
[ ] No [Go to Item 20]
[ ] Dont know [Go to Item 20]
15. Did the feeling of numbness or tingling occur only when you kept your arms or legs in a certain position?
[ ] Yes [Go to Item 20]
[ ] No
[ ] Dont know
16. Did the episode come on suddenly?
[ ] Yes
[ ] No
17. During the episode of sudden numbness or tingling, which part or parts of your body were affected?
[READ ALL CHOICES]
17a. Left arm or hand?
[ ] Yes
[ ] No

[ ] Dont know
17b. Left leg or foot?
[ ] Yes
[ ] No
[ ] Dont know
17c. Left side of face?
[ ] Yes
[ ] No
[ ] Dont know
17d. Right arm or hand?
[ ] Yes
[ ] No
[ ] Dont know
17e. Right leg or foot?
[ ] Yes
[ ] No
[ ] Dont know
17f. Right side of face?
[ ] Yes
[ ] No
[ ] Dont know
17g. Other?
[ ] Yes
[ ] No
[ ] Dont know
18. During this episode, did the abnormal sensation start in one part of your body and spread to another, or did it stay in the same place?

[ ] Started in one part and spread to another
[] Stayed in one part
[ ] Dont know
19. While you were having your episode of numbness, tingling or loss of sensation, did any of the following occur?
[INCLUDE ALL THAT APPLY]
19a. Speech disturbance?
[ ] Yes
[ ] No
19b. Paralysis or weakness?
[ ] Yes
[ ] No [Go to Item 19d]
19c. Did you have difficulty on:
[READ ALL CHOICES]
[] The right side only
[ ] The left side only
[ ] Both sides
19d. Lightheadedness, dizziness, or loss of balance?
[ ] Yes
[ ] No
19e. Blackouts or fainting?
[ ] Yes
[ ] No
19f. Seizures or convulsions?
[ ] Yes
[ ] No

19g. Headache?
[ ] Yes
[ ] No
19h. Pain in the numb or tingling arm, leg or face?
[ ] Yes
[ ] No
19i. Visual disturbances?
[ ] Yes
[ ] No [Go to Item 20]
19j. Did you have:
[READ ALL CHOICES UNTIL A POSITIVE RESPONSE IS GIVEN]
[ ] Double vision
[] Vision loss in right eye only
[ ] Vision loss in left eye only
[ ] Total loss of vision in both eyes
[ ] Trouble in both eyes seeing to the right
[] Trouble in both eyes seeing to the left
[] Trouble in both eyes seeing to both sides or straight ahead
F. SUDDEN PARALYSIS OR WEAKNESS
20. Have you ever had any sudden episode of paralysis or weakness on one side of your body, including your face, arm, or leg which lasted at least 24 hours?
[ ] Yes
[ ] No [Go to Item 25]
[ ] Dont know [Go to Item 25]
21. Did the episode come on suddenly?
[ ] Yes
[ ] No

CHOICES]
22a. Left arm or hand?
[ ] Yes
[ ] No
[ ] Dont know
22b. Left leg or foot?
[ ] Yes
[ ] No
[ ] Dont know
22c. Left side of face?
[ ] Yes
[ ] No
[ ] Dont know
22d. Right arm or hand?
[ ] Yes
[ ] No
[ ] Dont know
22e. Right leg or foot?
[ ] Yes
[ ] No
[ ] Dont know
22f. Right side of face?
[ ] Yes
[ ] No
[ ] Dont know

22g. Other?

[ ] Yes
[ ] No
[ ] Dont know
23. During this episode, did the paralysis or weakness start in one part of your body and spread to another, or did it stay in the same place?
[] Started in one part and spread to another
[ ] Stayed in one part
[ ] Dont know
24. While you were having your episode of paralysis or weakness, did any of the following occur?
[INCLUDE ALL THAT APPLY]
24a. Speech disturbances?
[ ] Yes
[ ] No
24b. Numbness or tingling?
[ ] Yes
[ ] No [Go to Item 24d]
24c. Did you have difficulty on:
[READ ALL CHOICES]
[] The right side only
[ ] The left side only
[ ] Both sides
24d. Lightheadedness, dizziness, or loss of balance?
[ ] Yes
[ ] No
24e. Blackouts or fainting?
[] Yes

[ ] No	
24f. Seizures or convulsions?	
[ ] Yes	
[ ] No	
24g. Headache?	
[ ] Yes	
[ ] No	
24h. Pain in the weak arm, leg or face?	
[ ] Yes	
[ ] No	
24i. Visual disturbances?	
[ ] Yes	
[ ] No [Go to Item 25]	
24j. Did you have:	
[READ ALL CHOICES UNTIL A POSITIVE RESPONSE IS GIVEN]	
[ ] Double vision	
[] Vision loss in right eye only	
[] Vision loss in left eye only	
[] Total loss of vision in both eyes	
[] Trouble in both eyes seeing to the right	
[] Trouble in both eyes seeing to the left	
[] Trouble in both eyes seeing to both sides or straight ahead	
G. SUDDEN SPELLS OF DIZZINESS OR LOSS OF BALANCE	
25. Have you had any sudden spells of dizziness, loss of balance, or sensation of spinning which lasted 24 hours or longer?	
[ ] Yes	
[ ] No [Go to Item 29]	

[ ] Dont know [Go to Item 29]	
26. Did the dizziness, loss of balance or spinning sensation occur only when changing the position of your head or body?	
[ ] Yes [Go to Item 29]	
[ ] No	
[ ] Dont know	
27. While you were having your episode of dizziness, loss of balance or spinning sensation, did any of the following occur? [INCLUDE ALL THAT APPLY]	
27a. Speech disturbances?	
[ ] Yes	
[ ] No	
27b. Paralysis or weakness?	
[ ] Yes	
[ ] No [Go to Item 27d]	
27c. Did you have difficulty on:	
[READ ALL CHOICES]	
[] The right side only	
[ ] The left side only	
[ ] Both sides	
27d. Numbness or tingling?	
[ ] Yes	
[ ] No [Go to Item 27f]	
27e. Did you have difficulty on:	
[READ ALL CHOICES]	
[] The right side only	
[ ] The left side only	
[ ] Both sides	

27f.	Blackouts or fainting?
	[ ] Yes
	[ ] No
27g.	Seizures or convulsions?
	[ ] Yes
	[ ] No
27h.	Headache?
	[ ] Yes
	[ ] No
27i.	Visual disturbances?
	[ ] Yes
	[ ] No [Go to Item 28]
27j.	Did you have:
[REA	AD ALL CHOICES UNTIL A POSITIVE RESPONSE IS GIVEN]
	[ ] Double vision
	[ ] Vision loss in right eye only
	[ ] Vision loss in left eye only
	[ ] Total loss of vision in both eyes
	[ ] Trouble in both eyes seeing to the right
	[] Trouble in both eyes seeing to the left
	[] Trouble in both eyes seeing to both sides or straight ahead
	Did the episode of dizziness, loss of balance, or spinning sensation come or denly?
	[ ] Yes
	[ ] No

Protocol source: <a href="https://www.phenxtoolkit.org/protocols/view/130301">https://www.phenxtoolkit.org/protocols/view/130301</a>